THE NEUROLOGICAL ALLIANCE

Impact of a no-deal Brexit on people with neurological conditions

- The Neurological Alliance's Response to the Health and Social Care Committee's inquiry into Impact of a no deal Brexit on health and social care

The Neurological Alliance is responding to this inquiry as a patient organisation whose member organisations are concerned about the impact on their condition communities of a no-deal Brexit. As a patient representative organisation it is difficult for us to given evidence on the exact impacts of a no-deal Brexit on patients. This is because we are not equipped with detailed knowledge around drug and devices origins and supply chains, or the operation of research. We will therefore be responding from the perspective of potential risks to patient care, and what this would mean for patients.

Supply of medicines, medical devices and technology

Any interruption in the supply of medicines, medical devices and technology could have a huge impact on both diagnosis and treatment of patients with neurological conditions.

Diagnosis of many neurological conditions requires the use of medical technology. In some cases, the use of these technologies could be impacted by any supply issues or trade difficulties arising from a no-deal Brexit. For example, MRI scanners depend on helium to keep them going. If there were any interruption to the supply of helium such that MRI scans were rationed, non-acute patients such as those awaiting a diagnosis or planned operations would most likely be lower priority. For these patients, diagnosis could consequently be delayed. The impact of delayed diagnosis on patients can include permanent neurological damage, more rapid or irreversible disease progression, worse quality of life, and earlier mortality.

Similarly, interruptions in the supply chain of both medicines and medicinal products would have a huge impact on patients, particularly where treatment is time-critical. At worst, patients could be left at risk of death. This is the case for conditions where treatments control symptoms which could endanger patients' lives if left uncontrolled. One example is epilepsy, where SUDEP (sudden unexpected death in epilepsy) is a risk for those whose seizures are not controlled by medications. It is also the case where treatment is time-critical to prevent the spread of disease.

Another risk of death linked with interrupted supply of medicinal products used in treatments is an increased risk of suicide. One of our member organisations which helps patients with trigeminal neuralgia feels that this is a real risk for people with this condition, as these patients would be left in agony.

Even where patients aren't at immediate risk of death, the impact on their condition of not getting medicines on time could be huge. Delaying even for a few hours can result in patient's losing their ability to manage their symptoms. They may suddenly not be able to move, get out of bed or walk down a corridor. Some drugs, such as those for wakefulness or sleep have very nasty side-affects

when supply is interrupted. This has happened before when suppliers have changed or production has transferred between countries. A no-deal Brexit could be a prime cause of this.

Any deterioration in people's control over their symptoms can be expected to result in a parallel increase in hospital admissions, with significant ramifications for an already overstretched health service. There would also be impacts on carers, who would be under increased dual strain of worry and increased caring responsibilities, and in some cases may need to take time off their paid work to look after their family members.

It is tempting to suppose that if there is an issue in the supply of particular medicines, similar products – such as brand/generic bioequivalents, could be used in the interim while the issue is sorted. While this solution is better than patients simply not having access to their usual medications, it is not without problems. Drugs with the same active ingredient still contain other ingredients, such as colouring and binding agents, which might affect how the drug is absorbed in the body. This means that higher, or lower, amounts of active ingredient reach the brain. If the level is higher or lower in one version than another, relapses or side effects could result. Moreover, having pills which look different can cause issues for people with memory problems, confusion, and co-morbid autism alongside a neurological condition. This can lead to errors in taking these medicines, and can also cause anxiety, which itself can cause relapses. Finally, for some conditions, there is no alternative medication.

Patients concerned about the potential impact of a no-deal Brexit on supply chains might be tempted to try and stockpile their medicines. Being able to do so is unlikely, due to limitations on people's ability to access their medications far in advance of when they will need them. Nevertheless this underlines the need to reassure patients that they will have access to their medications as and when they need them. As already mentioned, anxiety can impact people's symptom control, and contribute to relapses.

For all these reasons, it is essential that the supply of medications is maintained. This will require the government to work very closely with the pharmaceutical industry. It may also require preventative action, such as the ringfencing of funds to ensure appropriate stock is maintained.

Travel

In terms of travel, a no deal Brexit could have two major impacts. Firstly, it would end existing reciprocal healthcare arrangements, with nothing in their place. This would deny patients with neurological conditions the ability to access treatment in another EU country which cannot be obtained in their own. Secondly, it could impact the neurology workforce. While we would expect that skilled medical staff would qualify under any points-based immigration system, by imposing a visa system the UK would effectively be competing for clinicians in the same market as the US and Australia. This could lead to shortages of much-needed staff, and result in the NHS having to offer extra incentives to fill posts, which it can currently ill-afford.

Research

A no-deal Brexit could result in a loss of innovation and research developments which are necessary to save lives over the mid to long term. As an example, UK families bereaved by epilepsy pump-primed research of a wearable device to alert to sudden death, a UK innovation. Despite the project receiving no support from UK funding bodies, this potentially life-saving

innovation attracted €2 million European funding to the Spanish engineer entrepreneur (who has been based in UK for over ten years); something which could cease to happen in the event of a no-deal Brexit. Clinical trials are essential to research, as well as the only way some patients can access drugs they quickly come to rely on. Such trials can take place across different EU countries – which may no longer be possible.

At present many European neuroscience research committees are chaired by Brits. This will no longer be permitted under a no deal Brexit scenario – Brits may attend such committees but not chair them. This will be disruptive and impact research outputs. Similarly, UK researchers have played a leading role in bringing together consortia of the highest skills, resources and abilities to secure European funding such as Horizon2020. Existing research projects may be jeopardised, and future projects thwarted, in a no deal scenario. Given that many of these successful applications provide for translational, therapy based research, to identify the next generation of drugs with therapeutic potential, the exclusion or significant changes in how UK groups participate after Brexit will have an inevitable negative impact on UK research. It will limit the development of much needed treatments for devastating life-limiting diseases such as Neuronal Ceroid Lipofuscinoses (NCL) commonly known as Batten disease.

A no deal Brexit would have a particular impact on research into rare diseases, through being excluded from the European Rare Disease Network. We are particularly concerned about the impact of a no-deal Brexit on research into treatments and potentially a cure for rare neurological diseases. The nature of rare diseases in particular is such that being part of a wider population and working with EU patient groups and clinicians to have a collective voice can be very helpful.

On access to new medicines, departure of EMA and being a relatively small market compared to EU / USA / rest of the world may mean the UK is not a priority market for pharmaceutical companies. This will mean that patients who could benefit from drugs do not get access to them.

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